Ethics Article

ADVANCE DIRECTIVES: WHOSE WILL BE DONE?

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INTRODUCTION

A very good friend of mine underwent an aortic valve replacement and a mitral valve repair in September last year, at the age of 84 years. He had been very reluctant to have the surgery, but his increasing shortness of breath caused significantly impaired quality of life and greatly impacted his activities of daily living. He had also received very positive reports regarding the outcome of the operation from various acquaintances, most of them aged between 75 and 80 years at the time of their surgery. He had expressed reservations about having the operation to the cardiologist and the cardiothoracic surgeon, as he had partial bowel and bladder paralysis following a severe back injury sustained when he fell off scaffolding in his early forties. However, the general feeling was that he had a good chance of deriving substantial benefit from the aortic valve replacement and that the risk, while not insignificant, was outweighed by the potential benefits. At no stage was the issue of an advance directive discussed.

The initial surgery went well, but he required assisted ventilation for two days longer than anticipated, due to underlying chronic lung disease. His course in the ICU was complicated by haemodynamic instability, a toxic megacolon and renal dysfunction requiring dialysis. After one week, he was sufficiently stable to be transferred to the high care unit (HCU), where he developed an asystolic cardiac arrest after walking down the length of the ward. He was rapidly resuscitated and a temporary pacemaker inserted. A permanent pacemaker was placed a week later, after which he remained intubated and ventilated. Two weeks later a bowel perforation resulted in an emergency laparotomy, bowel resection and a colostomy. His wife gave consent for the procedure, as he did not have the capacity to give consent. The post-operative course was complicated by septicaemia; neither the organism nor the source of the sepsis was evident.

As he remained ventilator dependent, a tracheostomy was inserted; renal dialysis and inotropic support were continued. He was unable to feed orally, and so feeds were given via a nasogastric tube. He remained on antibiotics for most of his stay in ICU. He often appeared uncomfortable, in pain, with a very dry mouth, and unable to communicate with his family. He was confused at times and was physically restrained throughout his stay in the ICU. Almost six weeks after his initial surgery he suddenly developed severe hypotension, which could only be stabilised with such high doses of adrenaline that he developed gangrene of his extremities. Only at this late stage was a full family conference called, at which time they were informed that continued therapy was futile, and that the inotropic support would be withdrawn. He died 12 hours later, having endured a prolonged period of suffering. How different might his course have been if an advance directive or living will was in place? Should the surgeon and/or cardiologist not have broached the subject when discussing his therapeutic options?

This case also calls to mind the prolonged dying of the late Nelson Mandela, who was ventilated at the age of 95 years for about six months, despite reportedly being in a permanent vegetative state. Was it right to even initiate ventilation for him at this age? What were his and his wife's preferences? Had it ever been discussed with them by his medical team?

Both these cases illustrate the dilemma arising from the critically ill person requiring intensive care and assisted ventilation for a protracted period of time, particularly when the prognosis is thought to be poor. Usually the patient in this situation does not have the capacity to make healthcare related decisions for him- or herself, and the family does not know what to do. At what stage does this treatment become non-beneficial, and how and by whom should decisions be made regarding withdrawal of life-sustaining therapy?

This is where an advance directive, either in the form of a living will or an enduring health care proxy, may assist the family and medical team in their decision making.

WHAT IS AN ADVANCE DIRECTIVE?

An advance directive is "an instruction by a competent person regarding his or her medical or other health care decisions, which should be acted upon if and when he or she becomes incompetent and therefore unable to make such decisions."[1] Such statements usually take the form of advance refusal of specified treatments, but may also contain information about the patient's values and beliefs, and may be in the form of a living will, or an oral instruction to the doctor, family member or friend.[1,2] The living will specifies under which circumstances life-sustaining treatment, including artificial hydration and nutrition, should be

The Living Will is addressed to your family, your doctor and any health authority, and states:

"If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

"If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to be kept alive by artificial means, including ventilation or any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.
"DO NOT RESUSCITATE: I do not give my consent to any person's attempt at resuscitation, should my heart and breathing stop and my prognosis is hopeless."

Figure 1: Constituents of a Living Will adapted from: http://www.livingwill.co.za/document.htm

administered or discontinued. An example of a living will is available on the Dignity SA website, and is paraphrased in Figure 1.[2]

A different type of advance directive may be a health care durable power of attorney, where a family member or friend is authorised by the person to make decisions on his or her behalf, should he or she become incapacitated and unable to do so. This person may be endowed with the responsibility to make all or some of the health care related decisions on behalf of the patient (the "principal"). This is not the same as a legal power of attorney, in which case the person takes responsibility for the patient's financial affairs. Similarly, a living will is not the same as a last will and testament, which is only read after the death of the principal, and therefore the living will must be readily available to those people empowered with decision making on the principal's behalf.

According to Landman and Henley, the living will and health care durable power of attorney have important differences, despite both applying to the situation where a patient is no longer competent to make his or her own health care decisions.[1] The living will has a narrower ambit, and applies to patients who are at the end of life or in a permanent vegetative state, and concerns withholding and withdrawing of life sustaining treatment. The health care durable power of attorney operates in these circumstances as well, but may also be called upon to make decisions regarding incompetent patients in other health care situations as well.

THE ETHICAL FRAMEWORK APPLYING TO ADVANCE DIRECTIVES

The four principles of biomedical ethics are respect for autonomy, beneficence (to do good), non-maleficence (to do no harm) and justice.[3] In acknowledging that patients not only have the right to choose their medical treatment but also to refuse it, we respect their autonomy. Respect for autonomy incorporates the tenet of informed consent in health care, an important component of westernised medicine, together with respect for the patient's privacy and confidentiality. Informed decision making applies to any aspect of medical treatment, including acceptance or refusal of life sustaining therapy. In practice, while we readily accept the patient's decision in favour of treatment, refusal of medical treatment, particularly life sustaining treatment, leads to much angst and discussion among the health care team, and attempts to persuade the patient to change his or her mind.[4]

Advance directives promote patient autonomy by respecting the patient's right to make decisions about his/her health care in future when s/he is no longer competent to do so. They give the person a sense of control over what will happen to him/her at the end of his/her life, including decisions regarding institution or refusal of life supportive treatment. Advance directives also promote the principles of non-maleficence and beneficence, by avoiding harm and unnecessary pain and suffering, and promoting the patient's welfare.

Advance directives avoid the burdensome responsibility placed on the family to make decisions regarding end of life care without knowing what the patient's preferences would have been. They also guide the medical team in their decision making, although in cases when there is doubt regarding the patient's prognosis, the medical team may decide to disregard the patient's advance directive and institute life sustaining therapy, while negotiating the future course of action with the patient's decision makers.

THE LEGAL FRAMEWORK APPLYING TO ADVANCE DIRECTIVES IN SOUTH AFRICA

The first case in South Africa involving the right to die was that of *Clarke NO v Hurst and Others* 1992 (4) SA 630 (D), and it subsequently became a landmark legal case.[5,6] Dr Frederick Clarke, aged 63 years, was a doctor and a politician in the then province of Natal, who suffered a cardiac arrest while undergoing epidural treatment on 30 July 1988. He was successfully resuscitated, but suffered permanent brain damage and became vegetative. During his life time Dr Clarke was a member of the South African Voluntary Euthanasia Society (SAVES), and had signed a living will in which he directed that should he in future become terminally ill or permanently unconscious with no hope of recovery, he not be kept artificially alive but

be permitted to die. Three years after this incident Mrs Clarke applied to the court to be appointed curatrix to her husband, with the power to make decisions about withdrawing medical treatment, including artificial hydration and nutrition (AHN), from him. The Attorney General contended that death resulting from withdrawal of AHN would result in Mrs Clarke being held liable for his death, i.e. murder. Furthermore, the court refused to recognise the living will as a legally valid document.

Subsequently, the court came to the conclusion that, "judged by the legal convictions of the society, the feeding of the patient did not serve the purpose of supporting human life as it is commonly known. Accordingly, Dr Clarke's wife, would be acting reasonably and would be justified in discontinuing the artificial feeding. No wrongfulness would attach to Mrs Clarke's conduct."[5,6] Dr Clarke was discharged after artificial treatment was withdrawn, and died at his home in August 1992, four years after he had suffered the cardiac arrest.

What is the current situation in South Africa? Neither the living will nor the durable power of health care attorney is recognised by any statute in this country and they are therefore not legally enforceable.[2,7] However, the National Health Act (No 61 of 2003) does provide for a competent patient to appoint someone to make healthcare related decisions on his or her behalf if s/he should subsequently become unable to make such decisions, provided it is in writing. This instruction applies to both temporary and permanent incapacity, and would serve the purpose of appointing a surrogate decision maker for end of life issues as well.[7]

GUIDANCE FOR THE DOCTOR

The *World Medical Association Declaration of Venice on Terminal Illness* states that doctors are morally obliged to recognise and act upon living wills and advance directives.[8] Both the South African Medical Association and Health Professions Council of South Africa guidelines direct that advance directives should be respected, unless the doctor is uncertain and the situation constitutes an emergency, in which case treatment should be instituted unless the advance directive can be verified.[9,10]

In order for an advance directive to be valid, the following conditions have to be met:[2]

- The person writing the advance directive must be 18 years or older at the time of writing;
- The doctor must be certain that the patient was mentally competent at the time of drawing up the advance directive;
- A patient may only refuse consent to treatment if s/he has been fully informed about the illness and the proposed treatment; and
- The doctor must be satisfied that the patient did not change his/her mind after signing the advance directive.

CONCLUSION

A competent patient's refusal of treatment should be respected. An advance directive aims to explicate the patient's wishes at a time when s/he is unable to convey them personally, through incapacity.

Advantages of the living will include respecting the patient's autonomy, avoidance of unnecessary pain and suffering, and helping the medical team faced with difficult decision making. The disadvantages of the living will are the difficulty in making specific instructions clear to cover all eventualities, and the fact that the prognosis may be uncertain. The availability of a durable health care power of attorney may make the decision making much easier.

[The living will] "needs to be weighed, along with medical indications, estimates of future quality of life, and other expressions of the patient's preferences contributed by friends and family, in reaching a suitable clinical decision."[4] It should always be taken seriously, as it is an indication of the patient's autonomy. However, if there is doubt regarding the patient's instructions and preferences or his/her prognosis, the medical team should negotiate with the family for a period of time to reassess the patient's response to treatment. It is often helpful to discuss the living will within the medical team and with the family, and if necessary, request a clinical ethics consultation.

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